



The Birchgrove

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A Mother's Story !!

Heather is a single mother of a young daughter. She formerly ran a daycare centre out of her own home. There are many important themes in Heather's piece: discrimination, secrecy, sexuality and relationships. For years, Heather told no one that she was HIV positive for fear of losing her job, friends and lovers.

Heather describes her initial overwhelming need to be seen as a healthy person. She discusses the transition from a HIV person and healthy to someone living with AIDS.

The truth is having HIV totally screwed up my sex life. The man who was my lover when I found out was absolutely supportive and wonderful. We went on this journey together to find out about AIDS and he really supported me into digging about alternative things, in not buying the doctor's diagnosis, not reading newspapers and staying away from negative stuff. He wasn't afraid of me at all. In fact, I think he should have been more afraid than he was. But it was really good for me to have someone who could make love to me and not be afraid. We started using condoms and he had no problem with condoms. It was fine. In fact we had a lot of fun with them. But for other reasons I broke up with him.

My next lover is the man I am with now. He is really difficult for me to talk about, because I didn't tell him in the beginning. I was so convinced at the point when I met him that I was perfectly healthy, that I couldn't pass the virus to him and that the HIV was nothing. This was when I was really on a roll, very confident, so I didn't tell him that I was HIV positive. I am really sorry now. I know that it was wrong of me to make that kind of decision for him, that I exposed him to the virus without him knowing about it. For him to expose himself, knowing about it is one thing. But he didn't even have the chance to say no. I wasn't on birth control, so he was very careful because he didn't want me to get pregnant. I essentially practiced safe sex with him 99 percent of the time. But there two nights when we drank, came home from a

party and screwed on the kitchen table ...

When I finally did have intercourse with him on a regular basis, condoms were our form of birth control. I just told him that this is what I used for birth control.

I told him about four months into the relationship. It was really hard and I drove myself nuts knowing that I had to tell him. How do you tell someone that you have knowingly exposed him to AIDS. When I did tell him, I fully expected him to be really angry and to run, and I was ready for that. He pulled away a bit, but mostly he was concerned about me because I was an absolute basketcase. He went to his doctor and was tested. The result came back negative. He waited four or five months and was tested again and he was still negative. So he seems okay.

Since he has known, our sex life has gone downhill. Since I've been sick it's become almost non-existent, because he's afraid of me. He is very wonderful about it, but he's honest. He can't say he is not afraid of me when he is. He has three children and a business and too much to take care of. He was in a bad marriage for nine years.

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In this newsletter, we look at the subjects of well . . . there's quite a few actually, so I would suggest you just get on and read. As time goes on, this newsletter takes longer and longer to produce, we really need more contributions from you - the people it's aimed at.

Many years ago the message was "there nothing out there for positive haemophiliacs". So Birchgrove was born, but unless we get some help! It can also die!

Let's not go along that road.

COMMENTARY

Those of you who read this bit will remember that this issue should have been about Safer Sex for the Heterosexual Couples.

But we had very little response from the membership, with articles and such. So we have had to broaden out the topics covered. Hopefully you will get something out of this issue. If not, write and let us know. We are a very small team of volunteers who staff the office and produce all Birchgrove material. If we are wasting our time, let us know, as we are all positive haemophiliacs and we also live with a virus or two. We are planning a national conference which will take place sometime in 1998. A deposit of £50 will secure your place in advance of final details being released. Two nights in a hotel with workshops on: NAM "Treatments and Viral Load testing" and an Introduction to Chinese Herbs and Medicine. So let us know if your interested.

Take Care
Gareth

continued from front page

Sex is slowly phasing out and a good friendship is taking over. That process has been very slow. I know that is what he has wanted for months and I haven't been able to deal with it. He is just taking care of himself. In his head, he has wanted out since I got real sick. He just says, "This is ridiculous. I can't afford to expose myself to this." But his heart goes, "God, that is a real asshole thing to do, reject someone for their needs."

I answered his ad in the personals - that's how I met him. I was looking for a husband. I wanted to complete my family. I didn't want to be a single parent. I wanted to get married, have a couple more kids, buy a house, do what I had wanted to do in the first place. Since I have been ill, that has fallen by the wayside. It isn't likely that I will have any more kids now, because I'm not willing to deal with what I would have to deal with if my child was born with HIV. I know women who are HIV positive who are having kids. They are willing to deal with it and that's fine. But I know I would not survive losing a baby; it would just absolutely tear me up.

We realise that we are not going to get married and have kids together. We are just in a relationship. We see each other or talk on the phone almost everyday. Our kids spend a lot of time together. I spend a lot of time down at his business and aside from the sex, we're really good friends. We enjoy being with each other.

QUESTIONS ??

QUESTIONS TO ASK ABOUT TREATMENT

You may find it useful to ask these questions for any treatment you are considering or being offered. If you don't want to ask your doctor then another member of the health care team or the pharmacist can often answer these questions.

The more you know the better choice you can make.

- 1) What is the name of the drug?
- 2) What does it look like?
- 3) How and when do I take it?
- 4) What side effects might I experience?
- 5) When are the side effects likely to happen?
- 6) If I do get these side effects what can I do to help?
e.g.:
 - What can I take for a headache?
 - What do I do if I feel nauseous?
 - In what circumstances should I discontinue?
- 7) How will I know if the treatment is working and when might I be able to see the benefits?
- 8) What do I do if I miss a dose, or take too much? What are the implications if I miss doses?
- 9) Do I need to take the drugs on an empty or full stomach?
 - For how long before and after taking the pills should I not eat?
- 10) Are there any foods that I should avoid?
- 11) Do I need to be careful about drinking and recreational drugs on this treatment?
- 12) Are there any over the counter drugs that I should avoid when I am taking this treatment?
- 13) What do I do if I think I am pregnant or want to conceive?
- 14) How can I get further information about this treatment if I want it?
- 15) Do I need to think about taking time off work while my body gets used to taking these drugs?
- 16) Do these drugs need to be kept in the fridge?
- 17) Can I take them on holiday?
- 18) Could I stop taking them for a while and then start again if I wanted to?
- 19) How does this treatment affect my future treatment options?
- 20) What do I do if somebody else takes them by accident e.g. my child?
- 21) Should I drive a car or operate machinery while taking these drugs?

FIVE STEPS TO A HEALTHIER & SAFER SEX LIFE

1. Use a condom every time!
Condoms offer the best protection against sexually transmitted infections (STIs) for people having sexual intercourse.
In a 1987-1991 study of couples in which one partner had HIV, all 123 couples who used condoms every time for four years prevented transmission of HIV.

In 122 couples who did not use condoms every time, 12 partners became infected. A similar 1993 study showed that using condoms every time prevented HIV transmission for all but two out of 171 women with male partners with HIV. However, eight out of 55 women whose partners didn't use condoms every time became infected.
2. Talk with your partners before the heat of passion, and use a condom every time!
Partners should care about each other and be interested in one another's pleasure, comfort, and health.
Be open.
Let your partner know your health concerns and sexual health history, and encourage your partner to be open, too.

Be direct. Talk about your sexual needs and expectations.
Be persistent. Don't let your partner remain silent on these issues.
3. Keep medically fit, and use a condom every time!
Have a checkup for STIs every year.
Protect your immune system. Eat well, get enough rest, and limit your use of alcohol, tobacco, and other drugs.
4. If you think you or your partner has an STI, see a doctor for testing, diagnosis, and treatment.
Find out if your partner(s) need to be examined and treated, too.

Use all the medication that is prescribed – symptoms often disappear before an infection is cured.

Do not take anyone else's medicine, and do not share yours.

Do not have sex until your infection is under control ... then use a condom every time!
5. Stay in charge and use a condom every time!
Alcohol and other drugs weaken good judgment and self-control.

Don't let them jeopardise your self-control.

Condoms & Vaginal Pouches

Condoms are sheaths that fit snugly over the penis. Vaginal pouches – “female condoms” – fit inside the vagina. They protect against STIs by catching semen before, during, and after a man ejaculates (comes) and by reducing direct genital contact.

They also protect against pregnancy. Vaginal pouches enable women to take responsibility for preventing STIs and can be worn whether or not a man maintains an erection.

To use a vaginal pouch:

Fold the ring at the closed end of the pouch between the fingers of one hand

Insert the pouch deep into the vagina like a diaphragm

Let the ring at the open end hang about an inch out of the vagina

Lubricate generously with your favourite lubricant. Follow the directions on the package insert for more detailed instructions.

Pregnancy & Sexually Transmitted Infections

Some STIs can be passed from a woman to her developing foetus during pregnancy or to her child during birth.

Some can result in the death of the foetus in the womb. Others can cause serious birth defects, developmental disabilities, and other health problems for newborn infants – problems that can last a lifetime or even cause death. Pregnant women and women who want to become pregnant should consider being tested for STIs.

Don't Let Embarrassment become a Health Risk

Many people find it very difficult to talk about their sexual health. Some even find it shameful. But discomfort and shame can get in the way of common sense. They can keep people from taking good care of themselves and their partners.

Choose a doctor with whom you can be comfortable while discussing these issues.

Keep yourself healthy by speaking frankly and openly with your doctor about your sex life and your sexual health concerns.

Some doctors don't ask – so take charge and speak up.

Remember: Protecting yourself against sexually transmitted infections can reduce anxiety and make sex a lot more enjoyable.

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RUBBERS

How To Use Condoms

Use only condoms made of latex rubber. Latex is an effective barrier to HIV. Lambskin or natural membrane condoms are not effective because of the pores (tiny holes) in the material. Look for the word latex on the package.

Store condoms in a cool, dry place, away from heat and sun.

Use a new condom for each act of sex. Do not use a condom more than once.

Put the condom on the penis, sex toy, finger, or hand before contact with the vagina, mouth, or anus to prevent exposure to semen, blood, or vaginal fluids.

Roll the condom all the way down to the base of the penis, sex toy, finger, or hand. If putting it on a penis, leave a space at the tip of the condom for semen.

Use a spermicide (contraceptive cream, foam, or jelly) with the condom to increase protection during vaginal sex.

Use a water-based lubricant to help prevent condoms tearing and add comfort for vaginal or anal sex. Do not use oil-based lubricants (hand lotion, cold cream, baby oil, petroleum jelly, or shortening). These can cause the condom to weaken and tear.

Make sure the condom does not slip off. It may be necessary for either partner to hold the condom at the base to prevent it slipping off during sex.

If your partner is a man, have him take care in withdrawing his penis after sex (coming) to avoid spilling semen. Do not fall asleep before your partner withdraws his penis after sex, because semen could leak outside of the condom into your body.

CRYING OUT FOR A BABY

Dr Augusto Semprini at Milan's St Paulo Hospital was one of the pioneers and as a result the process has been available in Italy for some years. No one in Italy has become positive following insemination but there have been one or two cases in the US.

Sarah and David are one of the many couples who may benefit from sperm-washing. David is HIV positive and Sarah negative and they have already tried unsuccessfully to have children through donor insemination and adoption. David's HIV specialist raised the possibility of sperm-washing last November and the couple have now been referred to London's Chelsea and Westminster Hospital.

They are waiting to find out more about the technique before they make any decision and "have yet to really talk to each other about it," Sarah says. Having already been down two other routes to parenthood, they are still getting over their last disappointment - being rejected as adoptive parents.

"My feeling is that it does offer us hope," says Sarah. "But we have been so unlucky to date, we don't want to have unrealistic expectations. I am a bit worried about it - my concern would be the risk of transmission and whether the washing process itself could cause any harm to the sperm that transfers to the baby." Ironically, sperm-washing was the first option they considered in 1992, when they decided to start a family after living together for six years.

They were told then that they had five choices: sperm-washing, donor insemination, adoption, unprotected sex at the most fertile time of the month or not having children. The consultant said that most couples chose one of the last two options. Sarah and David asked about sperm-washing but were told that the hospital did not itself provide it on "ethical grounds" because there was still a risk that the virus was present. But it was available in Italy and the US.

"It all seemed so difficult at the time," Sarah says. "And, as having our own natural children wasn't paramount and there were other options, we didn't pursue it."

They considered the alternatives and ruled out unprotected sex. "David wanted to adopt from the start but I wanted to have the experience of giving birth, if possible," Sarah says. So they agreed on donor insemination. Their first hurdle was soon reached. As there is little NHS provision, they had to find a private clinic and they were left on their own. "Donor insemination is a big issue, particularly when you are forced to rely on private health care," says Sarah. "How were we to know whether a clinic was *bone fide* or not?"

But they did get information from the Landmark Centre in south London, including a list of the donor

Crying out for a baby

Sarah and David are prevented from having children because David has HIV. In the first of a two-part look at the problems surrounding sperm-washing – removing HIV from sperm – they tell their story to Anne Lawton

insemination clinics approved by the Human Fertilisation and Embryology Authority. Through it they found a "very supportive" clinic. But it was not cheap – £200 for each month Sarah attended.

The couple also considered the wider issues around donor insemination, particularly how and whether to tell the child. They were helped by a book, *The Gift of a Child*, and by attending a donor insemination support group.

The technique itself is quite basic. Sarah says: "The sperm is literally put on a spatula and inserted." But, to maximise the chances of pregnancy, it has to be done at the most fertile time.

"This means taking your temperature daily and testing for ovulation. Then, at the right time, you go into the clinic, preferably for two consecutive days." She found this quite stressful, particularly as she had not told anyone at her workplace and had to find reasons for suddenly needing time off.

The effort paid off. After four "cycles", Sarah was pregnant. But the joy was short-lived. Her first scan showed the foetus was dead and she had to have a termination. "It was a complete nightmare, I couldn't believe it. It was the last thing I expected to happen. I just stood there bawling my eyes out," she says. "It took me a long time to get over it. David was stunned but got over it quicker. For me, it was also a physical thing, my hormones were all over the place."

It brought back everything we had gone through when David was first diagnosed." Four months later, she went back to the clinic and this time conceived in the first month. But within weeks, she miscarried. Devastated, she went to a National Childbirth Trust support group but felt awkward. "Everything was heightened for me because of the HIV and donor issues," she says. "I didn't feel free to totally share the experience."

Sarah did try the clinic again but found the stress too much after four unsuccessful months. In the meantime, the couple had contacted their local authority about adopting a child.

"If you want to be accepted, you have to make a commitment not to try for your own child," she says. "So it meant I couldn't carry on, which was a relief in a way."

David and Sarah realised that they were "ground-breaking" by applying to be adoptive parents and were prepared for rejection. But they were still surprised by the ignorance they encountered about HIV and the difficulties they experienced.

It took 15 months before they were finally turned down. Throughout this time, they had to chase up or challenge the council at every stage. They battled on, overturning an initial doctor's report that turned them down flat on the grounds of David's health without examining him or speaking to his doctor, and explaining over and over again that having HIV did not mean David was "dying".

When they went on the training course for would-be adoptive parents, they found that while it had taken them 13 months to get that far, it had taken most of the others only five or six.

While HIV was not given as a direct cause for their eventual rejection, some of the issues around it were, notably that David and Sarah would only tell the child of David's HIV status if he developed AIDS and the belief that the couple had neither seriously considered the issue of loss nor had a strong enough support network.

David's past drug use was also cited as a factor, although it was proved that this was 10 years ago.

The couple accept that the council had a difficult decision to make, complicated by the requirements of the Children's Act. But they think

the decision is wrong. They would have given a loving and stable home to an older child, who might otherwise stay in care.

"We wouldn't have unrealistic expectations. We know that any child we adopted would already have had difficulties in their lives," says Sarah. "We would accept them, warts and all, and help them come to terms with their lives. And because of our experience of living with HIV and coming to terms with traumatic events, we would be able to give that child something others couldn't. If David became ill, we would handle it in a constructive fashion. And we would have the support of our extended families. There are no guarantees for anyone, that people will stay together and not die early."

The couple are now deciding whether to appeal against the decision. Looking back on their experiences over the past four years, Sarah says ruefully: "When we were first given all those options, we didn't expect to be going through every one of them." But she is also philosophical about it: "Our experience may seem bleak but we have been unlucky. And we have been living full and fulfilling lives while this has been going on. David's diagnosis was a catalyst for us to make the most of our lives and we are doing that."

Her advice to other couples in the same situation is to consider all options.

"We need to keep pushing back the boundaries" – but to go into them with their eyes open and with realistic expectations. And, she adds: "It is really important to keep it in perspective and not make the pursuit of having a family the only thing in our lives."

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WEIGHT LOSS

Weight loss, or wasting, is one of the commonest symptoms of HIV infection, and can occur at any stage of infection. It needs to be taken seriously because unintentional loss of weight is often a sign that you may have an active HIV-related infection or disease.

Malnutrition can also reduce the effectiveness of the immune system. Weight loss occurs when the body is using up more nutrients than it is absorbing from food.

- HIV itself can increase the rate at which the body uses nutrients (increased metabolism)
- HIV itself can alter the lining of the gut, making it harder to absorb nutrients
- other gut infections can cause malabsorption and/or diarrhoea
- you may eat less than you used to (and need to) because of loss of appetite during ill-health
- specific conditions may make it harder to eat, such as mouth and throat infections
- some drugs may suppress your appetite or cause side-effects that put you off food, such as nausea, vomiting, indigestion or altered taste

Preventing weight loss

The most important ways to prevent weight loss are to treat HIV-related infections promptly, and to ensure that your nutritional intake is adequate. It is much easier to prevent weight loss in the first place, rather than to try to regain it afterwards.

It is sensible to arrange to see an NHS dietitian soon after you are diagnosed HIV-positive, rather than to delay until you have already started to lose weight. Some large clinics have dietitians who specialise in the needs of people with HIV.

A dietician can help you look at your diet to ensure that you have an adequate intake of all the main types of nutrients, and recommend any changes to fit in with any drugs you are taking and to help you cope with problems such as nausea.

If necessary you may be prescribed food supplements or drinks to increase your nutrition intake. This is particularly important during or immediately after periods of ill-health.

You can help by taking symptoms, such as loss of appetite, persistent nausea and diarrhoea, seriously and seeking prompt medical advice. Your doctor may be able to help by treating the

cause, or offering medicines to relieve the symptoms, or if the problems are themselves caused by treatments, by prescribing alternative drugs.

Good hygiene when preparing food and thorough cooking will help to reduce the chance of getting gut infections such as Salmonella and Campylobacter. Other precautions such as boiling drinking water and avoiding contact with human or animal faeces can cut down the risk of contracting parasites such as Cryptosporidium.

Treatment with anti-HIV drugs often leads to a significant increase in weight. Effective anti-HIV therapy is increasingly seen as a key element in a strategy to avoid or reverse weight loss. By boosting the immune system, it may also be the best available therapy for gut parasites such as Cryptosporidium and Microsporidium, which are hard to treat directly.

Encouraging weight gain

If you have lost weight after an HIV-related infection, a dietitian may recommend increasing your calorie and protein intake to try to regain it. You might be offered appetite stimulants, although these tend to encourage weight gain in the form of fat, rather than muscle, which is more important.

Some clinics may prescribe a short course of anabolic steroids, to be used in conjunction with gentle weight-training exercise, or you may be offered the drug human growth hormone on an experimental basis. Some studies suggest that these can lead to increased muscle mass and improved survival.

DISCLAIMER

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group.

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Editor, Gareth Lewis

AILEEN GETTY STORY

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Aileen Getty is full of metaphors, imagery and lists of pronouncements about life, death and being a Getty, and she has paid dearly for her frankness. Her interviews stand as examples of what can happen to someone this young, beautiful, famous and sick with AIDS: you muster the will to speak up about your illness and get rewarded with shame.

Like I said, it would be nice to write about Aileen and not dwell on the peculiarities of the Getty family. It seems far more worthwhile, at this point, to dwell instead on what it means when Aileen says, as a woman who's taken the hard, long road to truth, that AIDS, in her words, "is a phenomenal gift."

"If it hadn't been for HIV, I would still be a victim," Aileen says. "Victimised by my parents, by my legacy, by life. I'd been in seven institutions, I'd had 12 shock treatments, I'd had seven miscarriages. I was anorexic, a self-mutilator. I'd been there and back." In the most simplistic terms, it sounds like she was making one desperate bid for attention after another. "Right," says Aileen. "and the ultimate attention comes from death, and now I've got AIDS. I think it's probably been a lifetime of trying to die in order to be loved."

When she welcomes me to her house with somewhat -- but not a whole lot reserve, I wonder not how the girl who had everything got so messed up, but how the woman whose father faxed her personal correspondence to an NBC television presenter remains so unguarded, so dangerously honest, in the presence of a journalist. "I don't have a choice," she explains when I ask her why she'd ever consent to another interview. "I feel a responsibility to be public, although it's not my nature to be public."

"I'm not always familiar with the things that I've said, because before I speak or do any interview, I always pray."

"It's a hell of an achievement to get sober with HIV," says Aileen, who believes in Jesus but not necessarily in church. "I'm terrified of the public and I'm terrified of interviews and I'm terrified of cameras, and I always pray to be a vehicle for something larger than myself. I always pray to not be myself so I don't really relate to anything outside of the situation right here. But when you're public domain you do feel industrialised. Fortunately, I don't suffer from it, I don't take it to bed with me. I live actually a very simple life, a very unglamorous life, a very real, good life. A real good life. I love my life."

It is early March, one of those stunning days in Southern California when the air is suddenly full of jasmine and the breeze is warm but as yet smog-free; the kind of day that makes it hard to think about leaving this world. The sun is beating down on Aileen's brutally sunny patio, but she is soaking in it, draped in a black dress over black suede Doc Marten boots, her long, silky brown hair brushed back over one side of her face. Her 12-week-old German shepherd puppy, Texas, scrambles around our feet and tugs at Aileen's sleeves, much to the dismay of Aileen's manager, Steve Grissom, who is doing his best to control a situation that will forever be out of any one's control. In his friend and client's

own best interest, Steve would really prefer that Aileen avoid talking too much about drugs and out-of-body experiences. But Aileen, ever the rebel, is adamant. "Don't avoid the drug issue," she advises in a voice made husky and nasal by cigarettes and tuberculosis. "It's not something I want to avoid. I think it's very important to deal with drugs and HIV. It's very prevalent. They're two separate diseases, both lethal. But just because you've got HIV, it doesn't automatically put alcoholism into remission." In fact, Aileen attests, AIDS too often exacerbates addiction. "Drugs are about control over fear," she says, "and when you have AIDS, your lack of control is all that much more evident. I tried to make up for that lack of being in control, with a lot of cocaine."

"That's definitely not the way to do it." It has been nearly three months since Aileen nearly died, of toxicity and weakness, in her doctor's office, and for nearly three months since she made a commitment to get sober. "I was clinically dead," she says. "I went through the whole out-of-body experience and everything; it was probably the clearest memory I've ever had. And there was a moment where I got to choose whether to come back or not, and I didn't know if I wanted to live. I have a lot of shame about that," she confesses. "Life is given to one with so much love. It broke my heart when I realised I'd turned my back on it."

Aileen chose life; she learned to "walk its circumference instead of fucking it down the middle." And she finally understood she didn't want either disease to kill her. "It's a hell of an achievement," she boasts, "to get sober with HIV because HIV was something that required a woman to stand up and speak the truth." Aileen's truth came in increments at first. She initially claimed that she'd become infected through a blood transfusion, but within the year, as her support increased and shame diminished; she admitted that she had contracted HIV from unprotected sex in an extramarital affair -- a disclosure that, at the time, led to the dissolution of her eight year marriage to Christopher Wilding, Elizabeth Taylor's son by Michael Wilding.

Aileen is now engaged to be remarried, to 40-year-old documentary filmmaker Jay Brown.

Aileen says about both her addiction and her HIV status. "Honesty has been really, really important" in her upbringing, and while there are many people who would take issue with that strategy, Aileen's defence of it hints at the deprivation she suffered in her own childhood. "I feel so strongly that if you deal with things in the present as they're happening, you have a far better chance of being able to cope with life, of being able to balance joy and grief, as opposed to trying to rehabilitate memories," she says. "Memories are not based in truth, and therefore they can't be treated symptomatically, appropriately. Everyone has a right to participate in one's life and in one's death. I think I would rob my children of something they have a right to, if I were not to tell them that I was supposedly going to die, or that I'm an alcoholic. They have that right to confront those challenges now, rather than later. And I think that often what we call grief after death

A Summer's Day

Love Sonnet XVIII

*. . . But thy eternal summer shall
not fade,
Nor loose possession of that fair
thou ow'st,
Nor shall Death brag to wander'st
in his shade,
When in eternal lines to time
though growest.
So long as men can breathe
or eyes can see,
So long lives this and this
gives life to thee.*

Shakespeare

Her sacred, naked body was turned by the nurses. This beautiful person with whom I had shared seven precious years was skin and bones. Deborah's thin, frail being was as lovely as when I first met her. 'Oh! How much I love you,' were the words streaming through my mind. Then it trickled painfully down my cheeks into the rivers of my emotions and finally, pouring helplessly, helplessly into the expanse of ocean, we call life.

Ironically, my first words to her when I met her was to ask if the drawing was a round face, with round eyes and ears and thick neck. "No," she replied, it was her body or at least, how she saw it. Her round eyes I realised were her breasts. Deborah was elegant, tall and slim built when we met on that introductory counselling course; not at all like the drawing. Just over halfway through the week, we had done this first one-to-one bit of work on describing the way we saw our bodies. (My drawing was full of deep blood reds, black razor edges cutting through swirling, bright crimsons of anger and rage of having haemophilia and at getting HIV. "What is this drawing about?" she asked. I described the incomplete truth of my rage and pain connected with haemophilia. She did mention some time afterwards, that she suspected it was also about HIV but she let it go.)

Now she is not here, I wonder if the sex part of our relationship was so important? I have not stopped loving her and my love grew more as we passed through one crisis of cancer to another. I do miss her physical body, her tender hand stroking my face; being able to touch her and remembering her hair caressing me as I used to give her one of my big bear hugs. Those physical contacts we take for granted are so important in love. After speaking to a few haemophiliacs, what has become apparent is that our sex lives are not all that brilliant. This

is a terrible admission for a haemophiliac, since throughout our adolescent years, we have tried to assure ourselves of our sexual prowess. I cannot speak for others but I knew that there were days when I could not get out of bed, to put any weight on my legs was too painful; and there were times when I could not get out of bed for other, more pleasurable reasons. Nowadays, it is because I am too tired, due to the viruses the Factor VIII manufacturers forgot to remove from the bottles, that make me feel like a wet rag in the morning.

I sometimes wonder if other haemophiliacs do not feel like having sex because they are not well; fear of infecting their wives or partners; too painful to talk about sex and HIV; bottling the feelings of loss and leaving their family without a father; or having started a relationship which had bigger problems than they could cope with. I also wonder if the pain and anger is silently bottled up, so there is no room to talk? I know one thing for sure, there was a lot of anger at the Women's Weekend this year. To me, it indicates that there is a lot of stuff to clear up; and haemophiliacs and their partners are not being properly supported.

Returning back to that counselling course, when Deborah and I talked into the long, sunlit evening about the ancient Greeks, who carefully distinguished between the different types of love. For example, there is *Philia* (friendship); *Hetairike* (mutual attachment of friends); *Erotike* (sexual desire); *Agape* (disinterested affection) and *Storge* (tenderness). She wrote out a fuller description of this in her letter to me and signed it - *with my agape & storge - Debby*.

In English, we use the one word and it becomes a most inadequate and dangerous, loaded word. Here was a letter from Deborah saying to me that her love was open, affectionate and tender. What I am left with is not the sex but those words of love she wrote when we met.

*Your love was shared by many people.
I thank you for this masterpiece
Gareth*

WHAT ABOUT PREGNANCY?

Women can become infected before, during, and after pregnancy by having sex or sharing needles and syringes with an infected person. Infected women who become pregnant have difficult choices to make because they may infect their babies during pregnancy or birth. About one-third of the babies, born to infected mothers, are infected themselves.

This is how most children with HIV have become infected. There are also a few cases reported of HIV-infected women who infected their babies through breast feeding.

If you are pregnant or considering pregnancy, talk to your doctor or health care provider. Consider getting HIV counselling and testing if you have any concern that you or your partner could be infected.

If you are considering artificial insemination, make sure that the donor has tested negative for HIV.

How Else Do Children Get HIV?

Some children have become infected with HIV from infected blood transfusions and certain blood products (used to treat diseases like haemophilia). This is now very rare.

Like adults, teens can get HIV through sex or by sharing drug needles or syringes with an infected person.

Children and teens who are sexually abused may be at risk of infection if the offender has HIV. If you know of a child or teen who is being abused by anyone, call the National Child Line Helpline 0800 1111 or NSPCC Child Protection Helpline 0800 800500.

What About Drugs?

Sharing needles or syringes for shooting or skin popping drugs are not safe. Sharing even one needle with someone who is infected can infect you with HIV. If you have shared needles, or if you have a sex partner who has shared needles, even once, you may have been infected.

EVEN IF YOU ARE OFF DRUGS NOW

Because HIV is spread through infected blood, do not use any needles that have been used by other people for tattoos or ear piercing or for injecting drugs like steroids, hormones, or

insulin, or other substances like vitamins. Do not share ANY object that can break the skin.

Both drugs and alcohol can affect judgment and impair thinking. People under the influence of drugs or alcohol are more likely to do things that put them at risk of becoming infected with HIV.

If you use drugs, try to stop and get help. To find out how you can get off drugs, call DAWN or Positively Women Client Line 0171 713 0222.

What Is The HIV Antibody Blood Test?

This test tells if a person has been infected with HIV by detecting antibodies to the virus in the blood (the body produces antibodies to fight off viruses that enter the bloodstream). The blood tests used today are over 99 percent accurate.

For more information about HIV testing and counselling, contact your local HIV/GUM centre, AIDS service organisation, or your doctor's clinic.

What Can I Do To Help?

- Know the facts about HIV and AIDS: Use what you have learned to help protect yourself. Share the facts about HIV and AIDS with your family, friends and co-workers.
- Set an example for others: Show support and caring for people who are infected with HIV and those who have AIDS. Remember, you can't get HIV from being a friend.
- Become a volunteer: Call your local Red Cross or AIDS service organisation to find out how you can help.
- Sponsor a blood drive or donate blood: Blood donations from healthy volunteers saves lives.

IT IS IMPOSSIBLE FOR A DONOR TO GET HIV INFECTION FROM GIVING BLOOD.

- Sponsor an AIDS fund-raising event or donate money.
- Become a Red Cross HIV/AIDS instructor.

Excerpted from the American Red Cross' brochure, "Women, Sex, and HIV"

WHO WILL BE AFFECTED?

The Department of Social Security (DSS) have recently announced a massive review of Disability Living Allowance (DLA) claimants. The reviews will begin in July 1997, and it is estimated that up to half a million people will be affected. The review is aimed at all people with disabilities who receive the highest rates of DLA, and it is not targeted specifically at people with HIV or AIDS. However, it is clear that a large number of people with HIV or AIDS will be either interviewed or will receive questionnaires as part of this review.

Who will be affected?

The Benefits Agency have said they will carry out home Visits for everyone receiving the highest rates of both the care and mobility components (approx. 250,000 people). Another 250,000 people who get both the higher rate mobility component and the middle rate care component will be sent a questionnaire. We understand that if you claimed DLA, or had your DLA reviewed within the last twelve months then you should not be included in this review, and should not be sent a questionnaire or be visited.

Why is this being done?

Last year the DSS carried out a random survey of DLA claimants. The results showed that about 12% of people were overstating their needs, or had failed to notify the DSS of a change in their mobility/care needs. Following on from this, the DSS have now decided to carry out a large-scale review. The DSS have said this current review holds with their philosophy of getting "the right benefit to the right person every time". However, the survey last year also showed that around 10% of claimants were being underpaid because they had not reported a deterioration in their condition. Unfortunately, there are no proposals from the DSS to tackle the significant level of underpayment of DLA.

Home visits

The home visits will be by appointment, so you should receive a letter notifying you of the date of the visit. If the date is not convenient then it's a good idea to contact the Benefits Agency as soon as possible to rearrange it. The visits will be carried out by DLA staff. Although they will receive some extra training, they are not doctors and are not medically trained.

- Try and arrange for a friend or your partner to be at home with you for moral support during the visit. If

at a later date there is any dispute over what was or was not said to the visiting officer, then they may be a useful witness.

- Don't let the visiting officer rush you. Take your time and make sure you give full details of all your mobility/care needs.
- The visiting officer may know little, if anything, about HIV/AIDS, so don't assume s/he will know what you are talking about. For example, you should describe any side-effects of medication you take; if you suffer from nightsweats or diarrhoea, then don't simply mention this but describe how it makes you feel and what care needs arise.
- If the visit takes place on a 'good' day, you should tell the visiting officer. Explain how your health varies and what your care needs are on a 'bad' day.
- It may help to make notes beforehand of the points you want to make. You may be asked to sign a statement. It should be an accurate reflection of everything you have discussed with the visiting officer. It is important that you ask her/him to add in anything which you feel has been missed out before you sign it. If you need to take your case to appeal later, it can be very difficult to argue against a statement which you have signed.

The questionnaire

The questionnaire which is being sent out is called form DLA250. The questions it contains are very similar to those on the initial claim pack. It is important that you complete the form as fully as possible.

- If you need more time to fill in the form, do contact the Benefits Agency as soon as possible and let them know.
- It's a good idea to get help with completing the form. You may be able to get help from a welfare rights worker, social worker, Citizens Advice Bureau or from the person who helped you with your original claim form.
- It may be helpful if you can send in a supporting letter from your own doctor.

What happens next?

The Benefits Agency will look at the evidence in the visiting officer's report, or in the questionnaire and decide whether your claim should be reviewed. The law covering DLA says that an award of DLA can only be reviewed in certain circumstances if there are specific grounds for the review. The most common ground for a review is that there has been 'a relevant change of circumstances'. If the evidence from the

Continued from page 10

visiting officer's report or the questionnaire shows there has been no change in your circumstances then the Benefits Agency should not be able to review your award of DLA and your benefit should continue. If there has been a change in your circumstances, then a review may be carried out. However, if you still have mobility problems and/or care needs then despite a change in your circumstances you may still be entitled to DLA.

What if I lose my DLA?

If as a result of the review your DLA is either stopped completely or reduced to a lower rate, then you can challenge this. You can request a further review, but you must do this within three months of the decision. If this further review is unsuccessful, then you can appeal (again within three months) to an independent Disability Appeal Tribunal. You should get advice from a welfare rights worker to help you with a review or appeal.

Will my income support be affected?

Your income support may include two premiums which are related to your award of DLA:

severe disability premium

If your DLA is reduced to the lowest rate care component, or if you lose the care component completely, then the severe disability premium will no longer be paid as part of your income support.

disability premium

If your DLA is stopped completely then you may lose this premium. However, you should still qualify for this premium if you get any component of DLA, even at the lowest rates. You may also continue to qualify for the premium if you have been too ill to work for at least a year. You should contact an advice worker to check whether your income support is being paid at the correct rate.

For further information contact :

The Macfarlane Trust.

The National Birchgrove Group.

The Haemophilia Society.

AILEEN GETTY *Continued from page 7*

is not grief but guilt, regret that we have not fully participated in the life of a loved one. There's more guilt to grief than sadness." Guilt is not an emotion Aileen Getty has much interest in these days, unless she's working on eradicating it from her life and, to hear her talk, from everyone else's. Her contention that "Often what we call 'grief after death' is not grief but guilt."

'AIDS has improved her life' is loaded and controversial, implying, as it does, that everyone who suffers a tragedy does so for a pre-ordained or at least meaningful - reason. I admit to her that when I recently broke my finger - a trivial accident to be sure - there was a part of me that wanted it to happen. "Well, not wanted . . ."

I start to modify that statement, but Aileen stops me. "No! Say it! Really, it's OK. I'm proud of you for admitting that! That's so cool."

"But it's radical," I remind her.

"People get angry when you talk about it, they think you're saying they caused their own troubles. It's only radical," she corrects, "because we're dishonest. There are no mistakes and no one's guilty of anything. I don't have bad parents, I haven't been a bad child. Everything that's been given to me and I've given has been exactly what's been needed, and what's been given to me has sustained my life to this day. And this day is perfect, therefore what's been given to me is perfect."

The view from Aileen's patio today is perfect indeed. Hollywood lies at her feet in a sprawl of low-lying buildings, and when the sun is in the right place - neither too low on the horizon nor too bright and high - you can see the Pacific Ocean sparkling from miles away. Although she has just had her third encounter with a stalker, the gate at the bottom of the driveway remains open to the world, a defiant gesture to the 'obese fear ghosts'. Aileen has been beating down for most of her life. Looking out on this vista, I wonder if she believes in her heart everything she's saying, and how long she'll believe it. How long she'll be able to sustain her strained soul on the love she says AIDS has left her with, after it stripped everything else away; the one thing she never had handed to her on that proverbial silver spoon.

She says AIDS is a phenomenal episode in history. "It's the greatest war we've ever fought, and the most cunning of all because all we've got are weapons. We're about artillery as opposed to love. And it's love that will heal this ailment." Aileen says now that she's dedicating her life, to eliminating the public's fear of AIDS and the people who have it. So that people can learn to share this virus with us." She is working on a book and a public service announcement for NBC. She'd like to do an HIV-related comedy show, something M'Vish. "My whole purpose," she concludes, "is to welcome people inside the burning house."

"And how, I wonder, do you do this?"

"By loving them. And knowing I can put out the fire."

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VIRAL LOAD

REPRINT FROM NAM PUBLICATIONS

Viral load tests, also known as HIV RNA assays, count the number of HIV particles in a sample such as blood plasma. RNA is the form in which HIV particles carry their genetic material. The result of a viral load test is described as the number of 'copies' of HIV RNA per millilitre (copies/ml). 10,000 copies/ml or lower is generally considered 'low' and 50,000 copies/ml or greater is 'high'.

Each test has a limit below which it cannot reliably detect HIV RNA. For the widely used kit made by Roche, this limit is currently 400 copies/ml.

Any sample with HIV RNA levels below this threshold is said to have a viral load that is 'below the limit of detection', or simply 'undetectable'. This does not necessarily mean that there are no HIV RNA copies/ml in that sample; just that the number is somewhere between zero and 399.

If you currently have an active opportunistic infection or recently received a vaccination, you may have a temporary increase in your viral load. In these cases it is best to leave a couple of months before having your viral load measured.

The Roche test used to be inaccurate when used to test people infected with HIV sub-types that are most common in Africa and Asia, but has now been improved. All the tests are now about equally accurate at measuring these sub-types.

Assessing prognosis

If you are not taking anti-HIV drugs, your viral load may provide clues to the likely course of the HIV infection if left untreated.

Among a group of people who have the same CD4 count, those with higher viral load tend to have more rapid disease progression than those with lower viral load.

If you are thinking about starting anti-HIV therapy, you may find it useful to have a viral load test. The result, along with other indicators such as your CD4 count and symptoms, may help you decide whether or not to start treatment.

Some doctors advise people who have very high viral load to take more powerful treatments, such

as combinations that include a protease inhibitor.

Monitoring treatment

Treatment with an effective anti-HIV regimen results in a fall in viral load. If you are starting treatment, or switching from one regimen to another, you may find it useful to have a 'baseline' viral load test before you start or change treatment, followed by a second test a few months later. The difference between the two may indicate the short-term anti-viral effects of the drugs.

There is growing evidence that this short-term effect can also predict longer-term effects on disease progression and survival. Drug combinations that produce the greatest initial fall in viral load, and the most prolonged suppression, also tend to have the best longer-term effects in delaying the onset of AIDS or death.

In some cases, combinations can reduce plasma viral load to below the limits of detection, even among people with low CD4 counts or who have taken anti-HIV drugs before. If your viral load is 'undetectable', HIV may be less likely to develop resistance to the drugs.

However, the drugs may not have such a powerful effect throughout the body, and the effect may not last. There is no evidence that people with 'undetectable' viral load are no longer infectious to others.

If you are taking anti-HIV drugs correctly but your viral load starts to rise again or returns to its baseline level, this probably indicates that the drugs' antiviral effects are waning, perhaps due to resistance.

However, doctors differ in the extent to which they recommend basing treatment decisions only on viral load results.

Some argue that the aim of treatment should be to achieve and maintain undetectable viral load. Others are concerned that with today's drugs this is unachievable for many people and will encourage them to change drugs too rapidly, until eventually they run out of options.

NAM can be contacted on: 0171 627 3200 or write to: NAM Publications,
Freeport LON277,
LONDON
SW4 7YY.

PARTNERS TAKE ON OXFORD

On the 7th of March this year, 70 women gathered together at the Moat House Hotel in Oxford. Everyone who attended is in some way affected by haemophilia and HIV. Some have husbands, partners, fathers or sons who are affected, a few have HIV themselves. Others have lost someone close to them. They all share a common bond living with the effects of HIV.

The reason for organising this event was to acknowledge these women who have shown great strength not only caring for loved ones who are affected by HIV, but also caring for other family members who are coming to terms with the distress that such a situation brings. The main aim of the weekend was for those women to feel a sense of self and to, in some small way, show our appreciation and support for the care and commitment they give every day.

There were various workshops which dealt with a variety of issues such as stress management, being a carer, complementary therapies, financial and benefits advice, to name but a few. They were all well attended with the complementary therapies workshop one of the most popular. The emphasis was for these women to have a break and choose the best way to spend their time. Informal groups chatted and shared experiences, some women explored Oxford or used the hotel leisure facilities.

It was a weekend of strong emotions with a strong sense of companionship and solidarity. As one person put it "very emotional facing things full on, listening and talking about it - it rips you up inside but afterwards you feel much better."

There were tears and laughter but the overall feeling was freedom, the freedom to "talk openly about HIV - no secrets". Knowing that within this group you could stop struggling to keep the pieces together, you didn't have to be seen to be coping, you could be bitter, angry, sad. You could for a couple of days let go and know that those around you understood and cared. Everyone had something to give, time to listen, a hand to hold or a shoulder to cry on.

There was hope too, some of the new treatments look promising. However no-one was under any misconceptions, they

had been there before and only time would tell if the treatments would work and time was always going to be the problem. But for now there was laughter and hope for a brighter future.

At the start of the weekend there was an overwhelming feeling of isolation, fear of the stigma of HIV and the repercussions for family members by those ignorant of the facts. As the weekend drew to a close this feeling of isolation had transformed into a powerful sense of community and support. Friendships were formed with some exchanging addresses and phone numbers.

For us, the organisers, Chris Harrington (Royal Free Hospital), Debbie Vowles (Terrence Higgins Trust), Julie Kershaw, Debbie Gillespie and Joan Doyle (Haemophilia Society) it was a weekend we shall never forget. For us it was an opportunity to meet and talk to women about HIV and find out what we could do to help. We realised early on that there was a feeling of abandonment and lack of support from the Haemophilia Society and that this weekend was the first real step towards better communication on all sides. It was a wonderful experience for all of us.

On Sunday as the weekend drew to a close it was very hard to say goodbye. For many it meant gathering their defenses and veiling their emotions so that on the outside they were again coping. Life would go on but you know you are not alone. For all those who participated it was a memorable experience and we hope there will be many more.

Thanks to the Birchgrove Group, the Terrence Higgins Trust, The Macfarlane Trust, all the workshop facilitators, the Haemophilia Society, and most of all all the women who participated.

A full report has been sent to the Macfarlane Trustees and Haemophilia Society trustees outlining recommendations for the future.

(Birchgrove will be the first to congratulate the organisers on this event and the Welsh Birchgrove women, who made it happen.)

A full report is available from the society

Editor